

2018 Election Platform - Background

What do health consumers want?

Consumers at the centre of health

Health Consumers Alliance of SA Inc (HCA) is committed to putting consumers at the centre of health in South Australia.

Consumers at the centre of health is about deep and persistent culture. It means that consumers are a fundamental part of the health system – from planning, through decision-making, implementation, evaluation and review. It also means that individuals are full partners in their own care.

The experience and views of consumers – and those who care for them – are acknowledged as integral to how we do health. It is understood that healthcare – both at the systemic level and for individuals – can only excel when there is the active and equal participation of consumers.

The Australian Commission on Safety and Quality in Health Care cites a body of evidence illustrating linkages between consumer-centred care – through strategies such as consumer engagement – and decreased readmission rates, lower healthcare-acquired infections, improved delivery of preventative care services, better functional status, reduced hospital stays and enhanced compliance with treatment regimens.ⁱ

In South Australia, a consumer-centred approach is supported by the Charter of Health and Community Services Rights.

HCA's calls to action in its platform for the 2018 South Australian election reflects our understanding that consumer-centred care is more than focussing on the consumer. It is actively and respectfully working with the consumer.

Who we spoke with

The six calls to action in the HCA Election Platform is based on our advocacy work and engagement with patients, consumers, carers, communities, our members and key stakeholders spanning 16 years.

Over the last 18 months, we have led forums, focus groups, and specific health reform consultations, providing broad strategic and representative consumer engagement. Our members' forum and digital media engagement have reinforced consumers want health care that is person-centred, focussed on well-being, and designed in partnership with service providers.

HCA urges evidence-based policy without the politics, based on research and consumer input at all stages to improve health outcomes and reduce costs.

Calls to action

HCA calls on South Australia's political parties and the incoming South Australian government to put consumers at the centre of health through the following commitments.

Consumer-centred care

Consumers must be partners in our health system - they should be the focus and consulted in decisions made about health priorities, service delivery and evaluation. Consumers must be full partners in their own care. We call for:

(1) An advocacy service for individual health consumers

Establish an advocacy service across the health system for individual consumers and carers.

Consumers and carers have consistently identified there is a gap in providing independent professional support and advocacy to the individual consumer or carer. The result is that at the time of potentially greatest need, there is "no-one to walk alongside them". It is this service gap that an independent advocacy service can fill. Providing support to consumers within the health system, it would reduce failures in communication, improve access to appropriate services and ensure the voice of consumers is heard by health and medical professionals. As such it would have positive results for both consumer outcomes and public health resources. This service would recognise and protect the rights of consumers, carers and their families.

This role differs from that of the Health and Community Services Complaints Commissioner, which receives complaints about health and community services in the state, however does not provide an advocacy role for consumers and carers.

In 2018-19, as a first stage, HCA calls on the state government to fund a consumer-led case study into the efficacy, role, structure and functioning of an independent advocacy service, with a view to establishing the service in 2019-2020. HCA has already committed internal resources to baseline research in 2018 which can inform a formal government-funded study.

(2) Consumers as partners in ongoing health reform

Establish a consumer-led council to guide health reform and quality improvement across the state's health system. Develop a statewide standard for consumer-centred care.

HCA has concluded the need for ongoing reform and improvement in quality within the state's health system is as vital as ever. Reform is successful when it is informed by consumers at every level of design, decision-making, implementation, evaluation and review.

Reflecting on recent health reform findings,ⁱⁱ HCA calls on an incoming state government to establish and fund a consumer-led council, facilitated by HCA, to co-design ongoing reform at the statewide level. Membership would include consumers, carers, representatives of stakeholder organisations, and senior SA Health staff. In keeping with its role in co-design, it would report to the Chief Executive of SA Health and have direct access to the Minister for Health.

A key role would be the development of a standard for consumer-centred care that applies to all SA Health activities and operations, including all local health networks.

System change

A priority for consumers is a comprehensive health strategy for SA, with joined-up community health, primary health and mental health services. We call for:

(3) A primary health strategy for SA

Develop a primary health strategy incorporating preventive health, health education and health literacy, addressing the social determinants of health.

Prevention is better – and cheaper – than cure.

The split of health responsibilities between the Australian and South Australian governments has impeded the development of a primary health strategy for the state. The time has come to bypass jurisdictional arguments and to create a statewide strategy that prioritises prevention, health education and health literacy. The strategy should address issues including the social determinants of health, and integrate social policy and health policy within the state bureaucracy as appropriate.

For a state government with primary responsibility for expensive, acute, hospital-based care, the clear advantage is cost-saving. But the state government cannot work alone. A first stage in developing the strategy must be wide community and consumer engagement, with particular reference to high-risk groups and SA's diverse population, in collaboration with the Australian government's primary health networks. As the state's peak health-consumer body, HCA stands ready to provide expertise and leadership in the development of a primary health strategy.

(4) Strategic reform for mental health clinical services

Develop an integrated mental health clinical services plan, to bridge the gap between the community and health service initiatives. This aligns with the SA Mental Health Strategic Plan.

HCA acknowledges the work of the SA Mental Health Commission and the state government in developing the South Australian Mental Health Strategic Plan 2017-2022.ⁱⁱⁱ In particular, HCA acknowledges the extensive community consultation undertaken by the commission in devising the plan. The key themes of the plan match those HCA has identified across the health system: early intervention, community education, seamless services, quality, support for diverse communities, and leadership and governance.

What the plan does not provide is an integrated mental health clinical services strategy for the state. Serious systemic failures, such as at the Oakden Older Persons Mental Health Service, make such a strategy an imperative, as do mental health statistics. For instance, almost half of all South Australians aged 16 to 85 years will experience symptoms of mental illness at some time in their lives.^{iv} A holistic, world-class and strategic approach is needed to ensure clinical care that does not fail South Australians.

Health for those with the greatest need

Language, culture, gender and age, where you live and how much you earn should not be barriers to health and wellbeing. We call for:

(5) Access to in-home palliative care and end-of-life information

Expand access to in-home palliative care and information for consumers on palliation, end-of-life options and advance care directives. This aligns with Palliative Care South Australia's plan.

Consumers and their families want more information about palliative and end-of-life care options and have expressed the desire for more in-home services. These would allow more people to die in their own homes rather than away from what is familiar and loved. Funding for in-home palliative care currently fails to meet the demand, especially of an ageing population. HCA urges increases in funding as well as pilot programs into the efficacy of ehealth for in-home palliation.

The introduction of the *Advance Care Directives Act 2013* has been an important step in empowering consumers to receive the types of treatment and end-of-life care they prefer. However, introduction of the legislation has not been supported by sufficient resources for communication and uptake. Strategies are required to increase the awareness of advance care directives, including among healthcare professionals, and the take-up among South Australian consumers. This will require a funded public campaign supported by personal support for completion of directives by individual consumers.

(6) Culturally appropriate healthcare

Expand training and compliance to deliver culturally appropriate and non-discriminatory healthcare within SA Health, for Aboriginal, culturally and linguistically diverse, LGBTQI and older South Australians.

SA's healthcare has made important advances in culturally and linguistically appropriate services. A less piecemeal or 'tick box' approach is now required to reduce disparities in healthcare outcomes among South Australians.

Best-practice care is supported by research evidence, consumer and community experiences, cultural competency policies, and practices applied across the entire health system.^v It is most successful where competencies are embedded in the training (pre- and during-employment training), performance assessment and compliance standards required of staff at every level of an organisation. It requires not only cultural competence but cultural change.

Health outcomes improve for diverse communities when they are involved in the design of care that addresses their needs. HCA therefore urges a consumer-led expansion of workplace practices that promote culturally and linguistically appropriate care in the state's public health system, including for Indigenous, culturally and linguistically diverse, LGBTQI and older South Australians.

Consumers also want:

- **Aboriginal employment in the health and medical professions**

Increase the number of Aboriginal people employed as health managers, and health and medical professionals, by collaborating with associated training, government and Aboriginal organisations.

The disparities in health outcomes for Aboriginal people continue despite the *Closing the Gap* accord and a range of health policies developed for Aboriginal people. A contributing factor to poor rates of achievement has been the absence of Indigenous Australians in health and medical professions and within formal support structures.^{vi} As a result, services for Indigenous Australians have been on the whole culturally inadequate and, in some cases, racist.^{vii}

Involvement of Aboriginal people at all levels of health and medical care is therefore critical for future success, as is their presence in the decision-making levels of health policy. This requires an integrated approach with education and training bodies, recruitment and HR agencies and the Australian government – which bears shared responsibility for Indigenous policy – to attract Aboriginal people to health-related professions and develop support and pathways that will assist their success at every stage. An incoming state government should escalate current action in this area, with the development of policy and programs led by Aboriginal South Australians. Particular consideration should be given to the challenges of remoteness faced by some Aboriginal communities.

- **Informed consumers as partners in their healthcare**

Improve consumer access to their records, service and system information, and health and medical research, giving them informed control of their healthcare.

Consumers are clear – they want to be active partners in their own healthcare. To do this they need full access to their medical records. They need a health service culture that ensures respectful, fully informed participation at every stage. And they need access to research communicated with clarity which is readily available to the state's diverse populations. The evidence is clear: better health outcomes arise when consumers are partners in their own care. For the health system, this means savings.

To help consumers become informed partners in their healthcare, HCA calls for the SA government to review current practices considering, among other things, digitisation of patient records, deployment of EPAS across the health system, use of new technologies such as ehealth, public communication of research, and cultural and linguistic diversity. The purpose of this review would be to pursue measures to improve access to medical records, health system information and research. It should be consumer-led and include partners such as SA Health, the South Australian Academic and Health Science Translation Centre and the South Australian Health and Medical Research Institute.

- **Improved systems for reporting and accountability**

Considering recent failures to protect consumers within the health system, review and strengthen systems for reporting and accountability within SA Health.

Good governance is a hallmark of excellent healthcare. As a recent KPMG report found, public reporting stimulates quality improvement, especially at the hospital level.^{viii}

South Australia's public health system offers world-class services, yet failures in reporting, transparency, accountability and public communication continue to put consumers at risk. In some corners of the system a culture of secrecy has prevailed. Certainly, recent serious incidents such as chemotherapy under-dosing, breaches of patient privacy and unacceptable care within the Oakden mental health facility have their roots, in part, in poor governance.

SA Health's processes of reporting and accountability require radical review and reform, both at statewide and local health network levels. The review needs to be informed by the recommendations arising from reviews of recent incidents, by world's best practice (including around whistleblower protections), and with consumer involvement. The consumer-led council on health reform and quality improvement proposed within this platform would be well placed to provide consumer input and co-design principles.

- **Telemedicine and new communications technology services**

Further invest in telemedicine and new communications technology services for rural and remote communities, and for consumers receiving in-home or residential-facility care who have difficulty accessing external health services.

The use of telemedicine can reduce the burden of travel, improve access for people in rural and remote areas, reduce accommodation and parking costs, and reduce stress and waiting times. This is fundamental to consumer-centred care.

In South Australia, the SA Digital Telehealth Network currently provides the video and telecommunications technology for clinicians and consumers to communicate face-to-face from different locations. This greatly improves patient access to a range of clinical services, otherwise not offered in their locality.^{ix}

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ⁱ Australian Commission on Safety and Quality in Health Care (2011). *Patient-centred Care: Improving Quality and Safety through Partnerships with Patients and Consumers*. Sydney: ACSQHC.

ⁱⁱ Health Consumers Alliance of SA (2017). *Transforming Health Consumer and Community Engagement Committee: Activities Report 2015-2017*. Adelaide: HCA.

ⁱⁱⁱ SA Mental Health Commission (2017). *South Australian Mental Health Strategic Plan 2017-2022*. Adelaide: Government of South Australia.

^{iv} ABS National Survey of Mental Health and Wellbeing 2007; cited in SA Mental Health Commission (2017). *South Australian Mental Health Strategic Plan 2017-2022*. Adelaide: Government of South Australia.

^v Johnstone, Megan-Jane and Olga Kanitsaki (2009). 'Engaging Patients as Safety Partners: Some Considerations for Ensuring a Culturally and Linguistically Appropriate Approach'. *Health Policy* 90.1 (April 2009): 1-7.

^{vi} Health Performance Council SA (2017). *Aboriginal Health in South Australia: 2017 Case Study*. Adelaide: Government of South Australia.

^{vii} Health Performance Council SA (2017). *Aboriginal Health in South Australia: 2017 Case Study*. Adelaide: Government of South Australia.

^{viii} KPMG International (2017). *Through the Looking Glass: A Practical Path to Improving Healthcare through Transparency*. Sydney: KPMG.

^{ix} SA Health webpage (2017). *Telehealth*. <http://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/Health+services/Telehealth/> Adelaide: Government of South Australia.